

EMPIRICAL STUDY

A bridge between a lonely soul and the surrounding world: A study on existential consequences of being closely related to a person with aphasia

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Abstract

This study illuminates existential consequences of being closely related to a person suffering from aphasia. Seventeen close relatives were interviewed and their narratives were interpreted with inspiration from Ricoeur, Levinas, Husserl, Winnicott, and Maurice Merleau-Ponty. The emerging interpretations resulted in four themes that illuminate a life characterized by lost freedom, staying, a new form of relationship, and growing strong together with others. An overarching theme suggests that a life together with an aphasic person means being used as a bridge between the aphasic person and the surrounding world. Moreover, it illuminates that a close relative to a person with aphasia is a person who does not leave, despite a heavy burden of lonely responsibility. It is concluded that community services need to fulfill their responsibility of providing support to informal caregivers as suggested by the Swedish lawmakers.

Key words: *Close relatives, stroke, aphasia, community service, life world, hermeneutics*

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This study is part of a Swedish project on aphasia from the perspectives of those who suffer from it and their close relatives. Previous research investigated existential issues (Nyström, 2006) and professional aphasia care from a patient perspective (Nyström, 2009). The present study illuminates existential consequences of being closely related to a person with aphasia.

Background

About one-third of patients with acute stroke also suffer from aphasia, and Laska, Hellbom, Murray, Kahan, and von Arbin (2001) found that 43% are still affected 18 months after onset. There are many types of aphasia, but all have in common difficulties in naming, finding, understanding, and/or producing words. This can affect all aspects of verbal communication, i.e., speaking, reading, writing, but also nonverbal communication such as gesturing (Rychener, 2006). Hence, persons affected by aphasia have to deal with abrupt changes in their daily

life, often with feelings of loneliness, anxiety, and humiliation.

Moreover, aphasia seems to include impaired skills of understanding and having an interest in other people (Nyström, 2006), which in turn is in accordance with Mead (1934), who stressed that interpersonal relations presume an ability to assume the role of the other and address that person in a language that he or she understands. A mutual communication is necessary for genuine interaction, cooperation, and depth of interpersonal relations. Thus, it seems fair to assume that aphasia has great impact, not only on the affected individuals but also on those closely related to them.

Research on closely related persons to stroke victims often focusses on their importance as informal caregivers (Lau & McKenna, 2001). A smaller amount of research directs interest to their own health problems in an abruptly changed life situation (c.f. Blake, Lincoln, & Clark, 2003; Sawatzky & Fowler-Kerry, 2003; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005) or to their

educational needs (O'Connell, Baker, & Prosser, 2003). According to Bäckström and Sundin (2007), close relatives to stroke survivors often give up on themselves and neglect their own needs. Wallengren, Friberg, and Segesten (2008) described such experiences as being "shadows," partly because they are invisible to professional caregivers, who tend to focus exclusively on the patients but forget their families. Close relatives' ability and willingness to understand and respond to an aphasic person is nevertheless of vital importance. This stands in contrast to the little attention paid to their specific problems or need of support.

Of the Swedish population, approaching 10 million people, approximately 30,000 persons are hit by stroke every year. About 25% of surviving stroke victims suffer from aphasia. Many of them are depending on close relatives for care and support.

To support informal caregiving, Swedish social legislation (SoL Chapter 5 §10) demands the social board in each community to provide for relief and other forms of concrete support for close relatives functioning as informal caregivers. Specific support must be based on knowledge about being informal caregivers. That is why the goal of this study is to contribute to such knowledge, with the specific aim of understanding existential consequences of being closely related to a person with aphasia.

Design of the study

The design of the study is exploratory within a lifeworld hermeneutic approach suggested by Nyström (Dahlberg, Dahlberg, & Nyström, 2008). This approach is influenced by Gadamer (1997) and his motto that a hermeneutic attitude demands an optimal consciousness to one's "history of effect" (p. 300), i.e., the researcher's preunderstanding, to increase validity of the suggested interpretations (Nyström & Dahlberg, 2001). To include explanations in the process of interpretation, the interpretative procedure was also influenced by the hermeneutic philosophy of Ricoeur (1976).

Participants and collection of data

The study was conducted in Sweden. Participants were purposefully chosen via aphasia associations. To obtain variation in the data, they differ in age and gender. Due to presumed variations in community services, they were also selected from three different communities. Seventeen close relatives were asked to participate: 11 women and 6 men aged 35–79 from the west and east of Sweden, from one big city as well as two smaller towns surrounded by rural areas. All agreed to take part in the study.

Their relationships to aphasic persons were 10 spouses, 6 adult children, and 1 parent. Those referred to as affected from aphasia were 11 men and 6 women, aged 25–88.

The interviews followed the principles of an open lifeworld approach (Dahlberg et al., 2008) and began with the question: What is it like to be closely related to a person with aphasia? The participants were encouraged to describe their personal experiences and actual life situation as deeply as possible. Pliable probing questions were put to make the interviewee reflect on matters not immediately described. The interviews were audio-taped and transcribed verbatim.

Analysis

The transcribed interviews were structured according to meaning. Meaning units were compared to identify similarities and differences. Units with similar meanings were separated from those who appeared to reflect other meanings. They were brought together in themes and four main themes emerged.

Each main theme covered one aspect of the research phenomenon, of being closely related to an aphasic person. Each theme was interpreted and finished with a suggestion of how to understand it deeper. The interpretations were inspired from elements of quite well-known theories introduced by Paul Ricoeur, Emmanuel Levinas, Edmund Husserl, and Donald Winnicott. Finally, an overarching theme was established that also took into consideration the abovementioned previous study in this project that analysed existential consequences of aphasia from the perspective of those affected (Nyström, 2006). The overarching theme was also inspired by an element in the philosophy of Maurice Merleau-Ponty.

To handle the issue of preunderstanding, i.e., check the validity, all interpretations were compared to the actual contents of the transcribed interviews. The researcher also searched for contradictions, other or better interpretations, and made sure that no data were omitted merely because they did not fit into any of the actual interpretations. If such weaknesses were found, the emerging interpretation was reconsidered, reworded, or simply left out.

Ethics

Information about the study was provided verbally as well as in writing, including the aim of the study, their voluntary participation, and right to withdraw at any time. All participants were assured of confidentiality. The findings are presented in a

way that protects the integrity and identity of those who participated or were referred to in the study.

Findings

In the findings, the four themes are described followed by the overarching theme. Quotations from the interviews illuminate the interpretative process.

Losing freedom

For close relatives, especially the spouses, community, and cooperation in one's daily life disappear when life abruptly changes after the onset of aphasia. One woman whose husband suffers from severe impressive aphasia says "I always have to consider the fact that his aphasia makes it frightfully hard for me to get in touch with him and that leads to loneliness for both of us."

This woman claims to be disabled herself due to her husband's communication impairment. Moreover, he takes her care for granted and is unable to understand that this puts both of them in a "prison." Another aphasic man dispatched community services without consulting his wife because he wanted her to "take care of everything." Both these women had to make an early retirement to take care of their husbands. Other spouses describe similar dilemmas:

That I want to do for myself I must give up, because it is a part of aphasia that they do not want to do anything by themselves, they want company all the time.

He knows what he wants and what he does not want, but I don't exist as a person anymore. He does not understand if I am tired or in pain. No, no, he says if I try to explain. So I am not allowed to have feelings.

I can't put any responsibility on her and trust her to do certain things. The whole responsibility lies on my shoulders, in all matters. I often ponder about my lonely responsibility that makes my life so restrained.

Living with an aphasic person, thus, means being taken for granted as an informal caregiver, whether you have agreed to it or not. Moreover, not any of the interviewees were ever asked by a professional from the community services, if they could handle such a situation:

The worst thing that could ever happen to me is to be caught in a situation as a next-of-kin

caregiver after retirement. Worst of all is the humiliation! No one ever asked if they had the right to destroy my life, and that is a deceit from the community.

It is devastating to always be restricted by another person's presence, even if it is your husband. You can indeed love a person, but not in a self-sacrificing way. You must have the right to live your own life! This right must be understood by those who decide about community services.

An adult son to a mother with aphasia emphasized the importance of knowledge. He believes that the lack of interest from the community services and political board is due both to lack of knowledge and to low status for all sicknesses that mostly affect older people. According to him, one manifestation of such attitude is that aphasia associations rarely receive financial support from the municipality, even when they ask for small contributions. They do not even respond to easy solutions to problems:

"Where I live, in my municipality, many computers are condemned every week. It would be easy to load them with programs designed for aphasic people and out them in a meeting place for persons with aphasia. But when I suggested that, they were not interested at all."

Hence, close relatives' freedom to make choices appears to be lost, especially for those living with the aphasic person. Their lost freedom can be interpreted from two different points of view. The first is the aphasic persons' decreased capacity to understand other people. The second, which highly contributes to fewer choices, depends on shortages in the community services. This forces close relatives to take on the part as informal caregivers, whether they have agreed to it or not.

When the French philosopher Paul Ricoeur (1966) illuminated the voluntary and the involuntary, he emphasized that only nature is involuntary. It is indeed impossible to escape the consequences of a brain injury. In this study, the close relatives appear to be well aware of the involuntary nature of aphasia, and they accept that. Yet, it is also obvious that the other aspect of decreased options is voluntary limitations as they are caused by humans; here shortages in the community service.

Choices presuppose possibilities to express one's wishes, and a sense of freedom depends on one's possibilities to say no. If informal caregivers have that possibility, it seems fair to assume that it would increase their capacity to deal with a difficult and

challenging life situation of being closely related to a person with communication impairments.

Staying

The close relatives in the present study did, however, make one important choice: they stayed. They knew that in similar situations, some people, especially spouses, would not. Some of the interviewees had considered divorce or, in some cases, their workmates had suggested it. Nevertheless, they did not find it a solution as it was impossible for them to leave a beloved one, even though a future life together seemed to be filled with problems. The choice to stay is even more obvious to those who are a parent or an adult child to an aphasic person. Yet, irrespective of relationship, they all emphasize that aphasia is the worst possible consequence of a brain injury.

“Aphasia is the most devilish of all the impairments due to stroke. I can accept that she is bound to a wheelchair, but the loss of ability to speak is unbearable. I don’t even know how she feels about it herself.”

Some linguistic capacity often returns after a while, but now changes in character and temper may occur. Bad temper is often directed toward those who are the closest. One husband puts it this way:

“I seem to fuel her anger merely by opening my mouth. She wants to decide everything. She has changed. She came back from her aphasia, but at the same time not. Our relation has become tenser. I think that we would have become closer if she never had that stroke.”

One daughter described her mother as a formerly cheerful person. But after a stroke resulting in aphasia, the mother uses bad words.

“My mother always liked to joke. Now she is rough; her words are vulgar and she uses bad language. The first word she said after her stroke was a curse word. I feel bad when I hear her talk like that, and I feel sorry for her because I don’t think she means it.”

A wife described her despair when her husband is angry at her most of the time: “It would never have happened before, that he was angry and irritated with me. Initially I told him how sad I was when he was angry at me, but now I have learned to stay calm.”

To understand the complexity of a person’s choice to stay, it is important to consider the fact that besides all frustration, sadness, and a heavy burden of responsibility, close relatives find that the aphasic person is helpless without them. Therefore, they try to keep in mind that an aphasic person’s loss of empathy with other people’s needs, as well as their bad mood, is caused by the brain injury. Consequently, it seems reasonable to understand their choice to stay as a duty. Irrespective of whether the decision to stay concerns spouses or parents or adult children, their motto seems to be, “for better or worse.”

The French philosopher Emmanuel Levinas (1972) recognizes the acceptance of other people’s right to be different from ourselves as an ethical issue. Such an attitude creates a distance from oneself and one’s own problems and opens up a space for demands from the other. Consequently, the duty to stay has an ethical component, as fundamental ethics mostly concerns interpersonal relations in general and people close to us in particular. Such ethical assumptions make it possible to place the aphasic person’s severe situation in focus, before one’s own problems.

Yet, the close relatives in this study did not talk about duty. They talked about love. Their love conquered all temptations to put their own life situation in focus. Love made them reject the idea about another life without the heavy burden of being closely related to a person with communication impairments. “My colleagues did advice me to divorce her. Nevertheless, I thought that this was something that had hit both of us, and I still love her.”

Creating a new relationship

The person who once existed is partly lost because of the brain injury, and this loss is indeed deeply recognized by the close relatives. Their sorrow does not merely concern the loss of verbal language but the whole person:

My dad was always cheerful and chatty. To lose that contact was hard for me.

I try to get in touch with my father, but it always makes me sad because there is only a part of him left.

The contact between my mother and me has deeply changed after her aphasia.

I cried in despair every day the first year. It was a total catastrophe.

Other interpersonal relations, such as friends and workmates, dramatically worsen for the affected person. Hence, one important part of the close relatives' sad feelings is to watch a beloved person's loneliness.

"My wife had many friends before she was ill. Now I believe that they were not real friends, because they never visit her. Nevertheless, I think that she thought that she had a rich social life before her brain injury. Now she doesn't seem to care, but I believe that they remain a disillusion to her."

The initial period with shock and sorrow successively turns into insight of the consequences of aphasia. Gradually, the sorrow is worked through, and a new form of relationship emerges. Now, it is also possible to see small gleams of light. "When you can reach into his consciousness, it is possible to recognize that he is still a man of intelligence." With limited possibilities to use words, the close relatives work hard to find new ways to communicate. Their inventiveness is huge; questions and guesses are supplemented with gestures, pictures, special noises, etc. Sometimes, it is easier to sing than talk. However, all such techniques take a lot of time. "You have to do twice as much in half the time. And you have to be well structured and predictable all the time." An adult child can transform to a parent to his or her own parent after the onset of aphasia. The easiest way out of such situation can be to concentrate on the practical things that need to be done. Searching for a new foundation in the relationship can also include new things such as buying a puppy or listening to music and singing together.

Spouses to aphasic persons told about decreased sexual desire. Yet, it did not necessarily mean that their closeness was lost. The more time spent for understanding each other could in fact lead to a new form of closeness. "We can sit and hold hands for quite a long time. We cry together and he dries his tears with my hand. So our relationship has changed, but not for the worse." Some alterations in personality can even lead to changes to the better.

"My husband cares much more about me than before the aphasia. He was very outward before he became ill, and he always wanted to do things with his friends. Now he is keener about me."

The initial period with chaos and shock eventually is replaced by mourning, followed by a period where it is possible to work through the

loss of an earlier relationship and adapt it to a new one. Ways to communicate are tried out and concrete solutions of problems emerge. The loss turns into commitment to the person that actually exists, with his or her communication impairments and changes in character. With this follows a new sort of relationship and sometimes a new form of closeness. The creative work of building a new relationship varies, and it fluctuates between despair, exhaustion, and acceptance.

Yet, there is something that does not vary. The close relatives search for a remaining essence in the aphasic person's personality. According to the German philosopher Edmund Husserl's phenomenological philosophy, an essence is described as a structure that makes a phenomenon that very phenomenon. This essence illuminates essential characteristics without which it would not be that phenomenon (Dahlberg et al., 2008), in this case the spouse, parent, or adult child who is affected by aphasia. In the close relatives' efforts to find a beloved person's essence, they separate impairments caused by the brain injury from characteristics they recognize and recall from the time before the injury. Hence, they search for a genuine personality that still exists. If this essence disappears, the beloved person is gone. But this is not true for any cases of this study:

Yes, he is emotionally shallow now, but his genuine feelings for me and the children are still there.

I think that her original personality, with a fighting spirit, was a lot of help to her when she started doing things again after her stroke.

The lovely girl whom I always had is still there. She hugs me when she visits us and when she returns to her nursing home.

I am pleased to notice that his strong will is intact, because that makes his life endurable.

The close relatives hold on to this essence when reaching the aphasic person, although verbal communication appears impossible. Hence, their new relationship builds on pliability with perceptions of the essence of the person who was there before the aphasia.

Growing strong together with others

As previously mentioned, two wives in the study were forced to quit their jobs, and many close relatives had no time for hobbies. Some of them

concealed their problems by putting up a façade in order to avoid putting more strain on the family, as they repel the idea that hardships would bring a family closer together. Moreover, they found the well-developed welfare system and community services in Sweden a myth. When discharged from hospital, the close relatives wrongly took for granted that community services included access to a speech therapist. They were not informed about the limitations in community services, especially after retirement in Sweden, i.e., 65 years of age. The only exception is a spouse who was lucky enough to be included in a research project.

“My husband participated in research and that included a speech therapist three times a week. The speech therapist also talked to me, and it was fantastic to be supported in my communication with him.”

Yet, all the other close relatives in this study were left alone with their fumbling efforts to find new ways to communicate. No professional caregiver ever taught them how to do this. Moreover, socializing with friends or alone time turned into somewhat of a luxury:

I feel so good when I have the opportunity to exercise and have coffee and a chat with friends. We discuss books, theatre, lectures, travels. We all laugh and talk a lot.

My dream is to be alone in my own home without obligations to wait for someone all the time. Or, imagine getting a whole night's sleep!

During such circumstances, being included in new forms of fellowship with other people in the same situation can be a compensation for the loss of previous networks and shortages in the community services. Membership in aphasia associations turns out important and valuable.

“In the aphasia association, I meet people who generously share their experiences; this makes me feel very good. It is easier with persons in the same situation.”

In aphasia associations, it is easier to take part in activities together with the aphasic persons.

“We enjoy travelling with the aphasia association. Such possibilities are worth a lot. Stimulation is really important, and being able to visit other countries gives a lot. Much of that pleasure remains when we return home again. We look at

photos together and remember many good things.”

Thus, it is a relief to find people in the same situations able to share their experiences. Such fellowships make it possible to create meaningful activities together with the aphasic person and enjoy moments of relaxation with other close relatives. An important aspect of such encounters is the ability to confirm and receive confirmation in terms of vulnerability as well as an unexpected capacity to deal with problems. Moments to oneself, or with others who are able to understand, make it easier to discover one's own hidden resources.

The British psychoanalyst Donald Winnicott (1971) introduced the idea that moments for active relaxation alone or with others constitute a “potential space” that makes it possible to work through thoughts and feelings. He claimed a potential space as an area between the internal life (fantasy) and the external world (reality). In the potential space, we have access to both. This makes it possible to reflect on problems and solve them, initially by imagining possible solutions and then by trying to solve the problem in one's mind. Therefore, a potential space is an important source for regaining strength. Hence, fellowship with others in the same situation and possibilities to alone time appear to increase possibilities to grow stronger than you could ever imagine.

“I have gotten a new insight. I think that all people have much more resources than they know. Human beings seem to have a kind of preparedness for dealing with difficulties but you are not aware of that until something happens.”

Overarching theme

The themes above, thus, illuminate four important aspects concerning existential consequences of being closely related to a person with aphasia. After onset, their life fluctuates between feeling imprisoned, when they understand that they cannot count on the community services, and a growing confidence in their ability to handle the situation. The way to better self-confidence is paved not only with setbacks, feelings of powerlessness, and despair but also with glimpses of hope.

A previous study of this project described how persons with aphasia feel empty in their internal worlds without having access to adequate words for their own brainwork (Nyström, 2006). Aspects of the same phenomenon appear to be reflected by the close relatives in the present study as they

become tied up with an aphasic person and lose opportunities to do things with other people or by themselves. Leaving the aphasic person alone is not an option because that would mean leaving him or her empty both in internal and in external sense. Therefore, they strive to find new things or new ways of doing old things together. During that process, they create a new form of relationship.

Being closely related to an aphasic person, thus, seems to comprise several important existential issues that all raise identity questions such as the following: Who was I before? Who am I now, when my possibilities to choose my own way of life is gone? What will I be in the future?

One tentative explanation to such an identity crisis is that the close relatives seem to take on the part of acting as an extension of the aphasic person's body and mind. According to Maurice Merleau-Ponty (1989), our "lived bodies" can be extended using *things* that increase possibilities to take part in the surrounding world. Some well-known examples from that element of Merleau-Ponty's philosophy are a cane or a pen that is experienced as a prolonged arm or hand, or music instruments or cars as extensions of one's body.

Merleau-Ponty also stressed that all forms of illness result in changed access to the world because of one's lost abilities and interruptions of harmonic living. This is indeed true when the most important part of the body, i.e., the brain is struck with illness. Aphasic persons find themselves in a situation where it is necessary to rely on other persons as extensions of their body and mind. Being closely related to an aphasic person consequently includes a tendency to be used as *thing*, in the sense that Merleau-Ponty suggests, or to put it more concretely, as a *bridge* between a lonely soul and the surrounding world.

Hence, a common denominator in the four themes described above concerns new ways of viewing oneself. The close relatives work through their present life situation beyond their earlier capacity. They decide to stay and continue to serve and love. By doing so, they also make a witting choice that makes them confident in their self-image as a person who does not desert a beloved person.

Discussion

The goal of this study has been to contribute to knowledge on existential consequences of being closely related to a person with aphasia, and thereby illuminate some conditions for informal aphasia care in the family. This is important because the Swedish community services are told by the government to

support informal caregivers to stroke victims, i.e., not only the affected person.

In this study, a difficult life together with an aphasic person is highlighted, especially for the spouses. The suggested interpretations illuminate existential issues brought to the fore by communication impairments. The close relative is used as an extension of the afflicted person's body and mind, i.e., as a bridge between him/her and the surrounding world. Yet, this is not the most frustrating part of the lost freedom; the lack of support from the community services is.

Therefore, it seems fair to put the question if politicians and social workers in Swedish communities pay the same attention to close relative's situation as the Swedish lawmakers. The findings indicate severe shortages in community services, especially for retired people in need of support. Some of these conditions could be predicted, that is why participants from different communities in Sweden were selected for the study. Yet, the only variation found in the conditions for informal caregiving was if the affected person was before or after the age of retirement or participated in research on rehabilitation.

In Sweden, there are no certain definitions for the concept "next of kin-carer" or "informal caregiver." As mentioned in the background, the Swedish social legislation (SoL Chapter 5 §10) demands the social board in each community to give relief and support to long-term informal caregivers. "The social board in each community *shall* provide support that makes it easier for those who take care of elderly persons or close relatives with long term illness or disabilities" (ibid.). But, this is obviously not true for all close relatives who are expected to become informal caregivers, even if it forces them into early retirement. Concerning younger people, a stronger form of legislation draws attention to their possibilities to a "normal" life. In the present study, this law was reflected by personal assistance to younger stroke victims and, in one case, special living arrangements in a community home.

Stroke and aphasia mostly affect older people. Yet, for those affected and their close relatives, this appears to be a disadvantage in a society where older people's needs generally are put aside in the competition with younger people's claim on health care and social service. Such reflections are in accordance with a recent study on the same target group (Nätterlund, 2010). This study also illuminates great changes in close relatives' lives; particularly earlier friends often disappear. Having an aphasic family member in need of support also creates a sense of emotional loneliness for those closely related. They regard themselves in charge

of the majority of the practical chores. Nätterlund accentuated the importance of support from rehabilitation and community staff to ease communication and cope with the aphasic person in everyday activities.

Wallengren, Segesten, and Friberg (2008) found that the key issue in becoming a close relative of a stroke victim during hospitalization means coming to a “turning point” where a life situation characterized by chaos turns into a search for order and stability. Such an attitude includes actively seeking professional caregivers for help. Nevertheless, in a follow-up 6 months later, the authors found them in the same situation. They still needed support from professional caregivers. It was concluded that it is important to consider close relatives as experts on their own life (Wallengren et al., 2008).

Many studies pay special attention to information needs, and several have found that during the acute hospital phase, close relatives mostly want factual knowledge about diagnosis, prognosis, and options (c.f. O’Connell et al., 2003). After the acute phase, requests for knowledge about how to assist the affected person emerge. When Wallengren, Segesten, and Friberg (2009) studied close relatives information needs, they found it essential to find ways of supporting this group. They highlighted the significance of identifying different areas of information and, at the same time, remaining open to their personal understandings and skills.

Since 1980s, education for close relatives can be included in psychiatric care (c.f. Das, Saravanan, Karunakaran, Ezhilarasu, & Jacob, 2006). During the introduction of such education programs, similar strives for aphasia patients and their relatives have been noted. For example, Lesser, Bryan, Anderson, and Hilton (1986) tested a program for its cooperative use by speech therapists and patients’ relatives at home. Both therapists and relatives approved the method.

In contrast to the development in psychiatric care, such educational approach appears not to influence the aphasia care of today. Only one interviewee in the present study had the opportunity to talk to a speech therapist, and that was because her husband was included in a research project. However, some efforts in a similar direction appear to take place in the UK, where van der Gaag et al. (2005) evaluated the impact of attending an aphasia therapy center that included counseling for individuals and couples. Improvement was measured by quality of life and communication. When Käcker (2007) studied communication between people with brain injuries and their close relatives, she suggested a theoretical model on how their communication could be manifested, which com-

prises the core process and the communication keys. The keys were found as introductory and maintaining factors as well as confidence factors. The latter had great significance; without it, communication failed to work out. According to Käcker, application of such knowledge also implies educational needs for close relatives.

Conclusion

The findings of this study imply far-reaching existential consequences in daily life for those closely related to persons with aphasia. They mostly result from the beloved one’s brain injury, but there are also existential consequences that appear unnecessary and a result of insufficient implementation of Sweden’s social legislation that since 2009 does make it compulsory for community services to support informal caregivers. If close relatives’ fundamental rights to decide on how to lead their lives would be paid attention to, probably it would also enhance their ability to give adequate care and support to their family member. It must also be possible for close relatives to continue their profession as well as have time for leisure activities and stimulating conversations with other people.

It is nevertheless urgent to keep in mind that the findings of the present study are limited to existential issues. The close relatives’ life situation as a whole has not been explored, and there might be several practical issues to consider when individualized specific professional support is planned in the community services. Such support can, for example, include education on speech training and counseling on practical as well as existential matters.

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References

- Bäckström, B., & Sundin, K. (2007). The meaning of being a middle aged close relative of a person who has suffered a stroke, 1 month after discharge from a rehabilitation clinic. *Nursing Inquiry*, *14*, 243–254.
- Blake, H., Lincoln, N. B., & Clark, D. D. (2003). Caregiver strain in spouses of stroke patients. *Clinical Rehabilitation*, *17*, 312–317.

- Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research*. Lund: Studenlitteratur.
- Das, S., Saravanan, B., Karunakaran, M. K. P., Ezhilarasu, P., & Jacob, K. S. (2006). Effect of a structured educational intervention on explanatory models of relatives of patients with schizophrenia. *The British Journal of Psychiatry*, 188, 286–287.
- Gadamer, H.-G. (1997). *Truth and method* (2nd rev. ed.). New York: The Continuum Publishing Company.
- Käcker, P. (2007). *Nycklar till kommunikation: Kommunikation mellan vuxna personer med grav förvärvad hjärnskada och personernas närstående och anhöriga*. [Communication between adults with acquired brain injury and their close relatives]. Dissertation, Linköping: Linköping University. The Swedish Institute for Disability Research at the Department of Behavioural Sciences and Learning.
- Laska, A., Hellbom, A., Murray, V., Kahan, T., & von Arbin, M. (2001). Aphasia in acute stroke and relation to outcome. *Journal of Internal Medicine*, 24, 413–422.
- Lau, A., & McKenna, K. (2001). Conceptualizing quality of life for elderly people with stroke. *Disability Rehabilitation*, 23, 227–238.
- Lesser, R., Bryan, K., Anderson, J., & Hilton, R. (1986). Involving relatives in aphasia therapy: An application of language enrichment therapy. *International Journal of Rehabilitation*, 9(3), 259–267.
- Levinas, E. (1972). *Humanisme de l'autre homme* [Humanism and the other man]. Paris: Fata Morgana.
- Mead, G.-H. (1934). *Mind, self and society*. Chicago: University of Chicago Press.
- Merleau-Ponty, M. (1989). *Phenomenology of perception* (Colin Smith, Trans.). New Jersey: Routledge.
- Nätterlund, B. S. (2010). Being a close relative to a person with aphasia. *Scandinavian Journal of Occupational Therapy*, 17(1), 18–28.
- Nyström, M. (2006). Aphasia- an existential loneliness: A study on the loss of the world of symbols. *International Journal of Qualitative Studies on Health and Wellbeing*, 1, 38–49.
- Nyström, M. (2009). Professional aphasia care – trusting the patient's competence while facing existential issues. *Journal of Clinical Nursing*, 18, 2503–2510.
- Nyström, M., & Dahlberg, K. (2001). Openness and pre-understanding – a relationship without hope? *Scandinavian Journal of Caring Science*, 15, 339–346.
- O'Connell, B., Baker, L., & Prosser, A. (2003). The educational needs of carers of stroke survivors in acute and community settings: Are they being addressed? *Journal of Neuroscience Nursing*, 5, 21–28.
- Ricoeur, P. (1966). *Freedom and nature: The voluntary and the involuntary*. North Western University press.
- Ricoeur, P. (1976). *Interpretation theory. Discourse and the surplus of meaning*. Forth Worth, Texas: Christian University Press.
- Rychener, H. M. (2006). The collaboration of music therapy and speech language pathology in the treatment of neurogenetic communication disorders: Part one: Diagnoses, therapist roles and rationale for music. *Music Therapy Perspectives*, 24, 58–65.
- Sawatzky, J. E., & Fowler-Kerry, S. (2003). Impact of care giving: Listening to the voice of informal caregivers. *Journal of Psychiatry Mental Health Nursing*, 10, 277–286.
- Socialtjänstlagen, *SoL kap. 5 § 10* [Social legislation law Chapter 5 § 10]
- Tooth, L., McKenna, K., Barnett, A., Prescott, C., & Murphy, S. (2005). Caregiver burden, time spent, caring and health status in the first 12 months following stroke. *Brain Injury*, 19(12), 963–974.
- van der Gaag, A., Smith, L., Davis, S., Moss, B., Cornelius, V., Laing, S., et al. (2005). Therapy and support services for people with long-term stroke and aphasia and their relatives: A six-month follow-up study. *Clinical Rehabilitation*, 19(4), 372–380.
- Wallengren, C., Friberg, F., & Segesten, K. (2008). Like a shadow – on becoming a stroke victim's relative. *Scandinavian Journal of Caring Sciences*, 22, 48–55.
- Wallengren, C., Segesten, K., & Friberg, F. (2008). Struggling for freedom – lived experiences of being a relative of a stroke survivor in the first six months after hospital discharge. *International Journal of Qualitative Studies on Health and Wellbeing*, 3, 230–238.
- Wallengren, C., Segesten, K., & Friberg, F. (2009). Relatives' information needs and the characteristics of their search for information – in the words of relatives of stroke survivors. *Manuscript in: De kan, de vill och de orkar men . . . Studier av närstående till personer drabbade av stroke samt granskning av informationsmetriker till svenska strokeenheter. Doktorsavhandling. [They can, they want and they have the strength but . . .] Högskolan i Borås och Karlstad universitet. Journal of Clinical Nursing*, 19, 19–29, 2888–2896.
- Winnicott, D. (1971). *Playing and reality*. New York: Basic Books.